

Complete Summary

GUIDELINE TITLE

Communicating with children and families: from everyday interactions to skill in conveying distressing information.

BIBLIOGRAPHIC SOURCE(S)

Levetown M, American Academy of Pediatrics Committee on Bioethics. Communicating with children and families: from everyday interactions to skill in conveying distressing information. Pediatrics 2008 May;121(5):e1441-60. [256 references] [PubMed](#)

GUIDELINE STATUS

This is the current release of the guideline.

All clinical reports, technical reports, and policy statements from the American Academy of Pediatrics automatically expire 5 years after publication unless reaffirmed, revised, or retired at or before that time.

COMPLETE SUMMARY CONTENT

SCOPE
 METHODOLOGY - including Rating Scheme and Cost Analysis
 RECOMMENDATIONS
 EVIDENCE SUPPORTING THE RECOMMENDATIONS
 BENEFITS/HARMS OF IMPLEMENTING THE GUIDELINE RECOMMENDATIONS
 QUALIFYING STATEMENTS
 IMPLEMENTATION OF THE GUIDELINE
 INSTITUTE OF MEDICINE (IOM) NATIONAL HEALTHCARE QUALITY REPORT
 CATEGORIES
 IDENTIFYING INFORMATION AND AVAILABILITY
 DISCLAIMER

SCOPE

DISEASE/CONDITION(S)

Pediatric conditions requiring effective communication with the patient and family, including:

- Surgical procedures
- Chronic illness
- Terminal illness
- Delivery room death

GUIDELINE CATEGORY

Counseling
Management

CLINICAL SPECIALTY

Critical Care
Emergency Medicine
Family Practice
Nursing
Obstetrics and Gynecology
Pediatrics
Psychology
Surgery

INTENDED USERS

Advanced Practice Nurses
Nurses
Physician Assistants
Physicians
Psychologists/Non-physician Behavioral Health Clinicians
Social Workers
Students
Substance Use Disorders Treatment Providers

GUIDELINE OBJECTIVE(S)

To provide research-based and practical guidance to enable effective communication with pediatric patients and their families in a number of common settings and situations

TARGET POPULATION

Pediatric patients and their families

INTERVENTIONS AND PRACTICES CONSIDERED

1. Effective, empathic communicating with patients
 - Causes of dissatisfaction
 - Audiotapes as communication aids
 - What parents want to know about surgical procedures and chronic conditions
2. Intraprofessional communication
3. Telemedicine
4. Communicating with children and adolescent patients
 - Enabling effective child participation
 - Adolescents and forgoing life-prolonging treatments
 - Legal and ethical issues regarding adolescent decision making
5. Cultural considerations

6. Use of translators
7. Giving bad news
 - In the emergency department, intensive care unit (ICU), pediatric ICU, neonatal ICU, delivery room
 - Terminal illness and palliative care
 - Postmortem communication
8. Informed consent, communicating risks, and benefits of research
9. Medical error disclosure
10. Physician self-care

MAJOR OUTCOMES CONSIDERED

- Patient satisfaction
- Parent/caregiver satisfaction
- Treatment adherence
- Patient health outcomes
- Practitioner medicolegal consequences
- Practitioner health outcomes

METHODOLOGY

METHODS USED TO COLLECT/SELECT EVIDENCE

Hand-searches of Published Literature (Primary Sources)
 Hand-searches of Published Literature (Secondary Sources)
 Searches of Electronic Databases

DESCRIPTION OF METHODS USED TO COLLECT/SELECT THE EVIDENCE

The Medline, Psycinfo, CINAHL, and Science Citation Index databases were searched in 4/2002 and again in 2005 and 2007. The following Medline Medical Subject Heading (MeSH) terms were used:

- Communication or truth disclosure or informed consent
- Physician-patient relations or physician's role or physicians
- Life change events or catastrophic illness or death or terminal care or palliative care
- Patient compliance or treatment outcome or bereavement or attitude to death or patient acceptance of health care or treatment refusal or patient dropouts or sick role or "medical home"
- Cultural characteristics or cross-cultural comparison or cultural competence
- Education, medical or "internship and residency" or students, medical

Inclusion criteria were pediatric, child, and infant studies. The exclusion criterion was studies published earlier than 1970.

In addition, the bibliographies of the papers identified through the literature search were reviewed, and the authors pulled relevant papers that had not been located through the search. The search was limited to papers published within the prior 20 years; some of the seminal literature cited in the papers was older, but still considered important to include.

NUMBER OF SOURCE DOCUMENTS

Not stated

METHODS USED TO ASSESS THE QUALITY AND STRENGTH OF THE EVIDENCE

Expert Consensus

RATING SCHEME FOR THE STRENGTH OF THE EVIDENCE

Not applicable

METHODS USED TO ANALYZE THE EVIDENCE

Review of Published Meta-Analyses
Systematic Review

DESCRIPTION OF THE METHODS USED TO ANALYZE THE EVIDENCE

Not stated

METHODS USED TO FORMULATE THE RECOMMENDATIONS

Expert Consensus

DESCRIPTION OF METHODS USED TO FORMULATE THE RECOMMENDATIONS

Not stated

RATING SCHEME FOR THE STRENGTH OF THE RECOMMENDATIONS

Not applicable

COST ANALYSIS

A formal cost analysis was not performed and published cost analyses were not reviewed.

METHOD OF GUIDELINE VALIDATION

Peer Review

DESCRIPTION OF METHOD OF GUIDELINE VALIDATION

Not stated

RECOMMENDATIONS

MAJOR RECOMMENDATIONS

Clinical Practice Issues

Communication with Parents: Ensuring Effective Communication

Factors predictive of effective communication between physicians and patients/parents are the perception of interest, caring, warmth, and responsiveness. Parents' most frequent criticisms of health care practice concern relationships with practitioners; these relationships have a dramatic effect on parental satisfaction, recall of instructions and, not surprisingly, treatment adherence. Greater trust and a better relationship with the physician have more of an effect on patient recall and satisfaction than written instructions or even the amount of time spent. (See Table 1 in the original guideline document for physician competencies for health care communication.)

Causes of Dissatisfaction

Even with very detailed explanations, parents who feel they are not treated with respect or who have unrecognized or unaddressed fears feel unhappy about the amount of information provided. For instance, being asked to consent to a new aspect of a procedure while standing in the hall the night before surgery caught 1 parent by surprise, coloring her overall satisfaction and perception of the sufficiency of information. Facilitators of improved communication include clear demonstrations of empathy and respect. See the Table below for additional recommendations.

Table: Recommended Communication Behaviors for Procedural Interventions

Find a private setting for discussion and decision making
Use language the family can understand
Use visual aids (drawings, models, and radiographs)
Pace the information, providing it in a logical sequence; be prepared to patiently repeat information and answer questions
Recognize emotional distress
Discuss indications, risks, benefits, and all reasonable alternatives (including not doing the procedure at all) and the associated risks and benefits
Discuss specific tubes and drains immediately before surgery
Personalize the information rather than giving it as a rote speech (e.g., use the child's name)

Avoid last-minute surprises when feasible

Ask parents and the child (when appropriate) to repeat what they understood in their own words, and clarify information and plans as needed

Data were adapted from Lashley M, Talley W, Lands LC, Keyserlingk EW. Informed proxy consent: communication between pediatric surgeons and surrogates about surgery. *Pediatrics*. 2000;105(3 pt 1): 591-7.

Audiotapes as Communication Aids

Several articles support the use of audiotapes to allow parents to repeatedly listen to the information, allowing it to soak in, and importantly, enabling dissemination of accurate information to others who could not be present. Parents frequently consult others in making health care decisions for their children, ranging from extended family members to other practitioners, other parents, religious leaders, and tribal elders. One study found that tapes made during outpatient encounters were listened to by parents nearly universally; grandparents listened to them more than half the time (52.8%), 70% were listened to more than once, and one third of parents made a copy to keep for themselves. The tapes were found to be helpful >99% of the time. Physician fears of the use of such tapes in medicolegal actions are understandable but, thus far, unfounded. In fact, the tapes often reveal that much more information was shared than either party realized, suggesting that the tapes may even be protective.

What Parents Want to Know: Surgical Procedures and Chronic Conditions

Patients undergoing surgery and their parents often want answers to seemingly "minor" questions. The expected duration of the surgery, the amount of hair to be removed, the location and length of the incision and bandages, location and purpose of intravenous lines and other assorted tubes, and the child's likely appearance after the procedure are sources of concern that, although routine for practitioners, should be prospectively addressed.

Parents consistently state that they need more and clearer information about their children's health status, particularly in the setting of chronic or terminal illness. Parents of chronically ill children want more information about the child's condition, its treatment, and its long-term implications; they want that information to be shared with them as soon as it is known.

Parents want advice about their child's behavior and development, genetic implications of the child's condition, and social contact with families in similar situations. They would like someone, preferably the physician, to provide oversight of the long-term care plan, including an opportunity for advance care planning and execution of advance directives. They want their views and concerns factored into the care plan and to be treated like partners (and often experts) in their child's care. They need affirmation of their efforts and assistance with and recognition of the need to preserve family solidarity and support, including social support, child care, education, and professional services; in some studies, parents report assistance with family and social support as their greatest unmet need. One proposed solution is to have an annual meeting of the family and physician to discuss the "big picture." In short, parents of chronically ill children want a

"medical home" as envisioned by the American Academy of Pediatrics (AAP). When appropriate information is not provided and this style of communication and relationship does not occur, the bitterness can linger for years. Physicians who are empathic, well informed, and honest are a source of strength for parents, particularly those struggling to adapt to a difficult situation.

Intraprofessional Communication

Particularly for children living with chronic health conditions, communication between primary care practitioner and specialist is critical for effective and efficient care. A recent study indicates that pediatric practitioners agree about the importance of such communication but have difficulty putting it into practice. Specific recommendations include timely, systematic information transfer from generalist to specialist at the time of referral, after consultation, and during follow-up visits. A toolkit with practical recommendations and reimbursement strategies can be found at <http://www.medicalhomeinfo.org/tools/toolkits.html>. In addition, recognition of the medical home concept and a plan for comanagement and communication should be in place.

Telemedicine

In the setting of rural health care and limited numbers of pediatric specialists, communication and medical care may be provided via video and audio conferencing. Even in the case of psychiatric illness and chronic illness requiring multispecialty input, parents and caregivers found this means of communication nearly as efficacious as in-person communication, particularly when combined with less frequent face-to-face consultations. Another application of telemedicine is to provide frequent updates and secure communication for parents and extended families and other practitioners when a child is receiving care in the intensive care unit (ICU).

Communication with the Child Patient: Ethical, Relational, Developmental, and Cultural Considerations

Moral, Ethical, and Developmental Obligation to Include Children in Communication About Their Health

There is a moral and ethical obligation to discuss health and illness with the child patient, which is supported by a number of United Kingdom, Canadian, and US laws, policies, and court decisions, indicating an expectation that children will be active participants in their care. The principle of self-determination applies to children and adults. Involving children in communication about their health and in decisions regarding their health care shows respect for their capacities, will enhance their skill in the process of making future health decisions, and enables their essential input into decisions where there is no "right answer" other than the 1 that best meets the needs of the individual child and family. Older children and adolescents should have a significant role in such cases. When the patient and family disagree, the cultural and family values, roles, and structure that have always governed the relationship should be treated with due respect.

Communication as a Developmental, Relational, and Cultural Process

At its core, child health decision making is family-centered decision making. Parents and children themselves are more satisfied and adherence to the treatment regimen is enhanced when the child is addressed in information gathering and in the creation of the treatment plan. However, parents want to be involved in the decision regarding how their children are informed about their health conditions. It is, therefore, important to understand the preexisting parent-child relationship, the family's cultural and idiosyncratic values, and the developmental needs of the child, including the desire to participate in his or her own care plan. Simultaneously, determination of the parents' perspectives on providing information to the child is imperative. It is important for parents to understand that research demonstrates improved adherence to the plan and resultant health outcomes when the child is treated as a partner. Pediatric health care quality will improve if the child is recognized to have his or her own individual cognitive and emotional needs, is taken seriously, and is considered to be intelligent, capable, and cooperative. Parents and practitioners should decide together whether the child will be present at the informational consultations, whether parents would prefer to tell the child themselves or have another person tell the child, and whether the informing interview will occur with or without the parents present. A recent literature review indicates that children 7 years and older are more accurate than their parents in providing health data that predicts future health outcomes, although they are worse at providing past medical histories. Thus, significant attention to the child's input should be routine practice. Assisting the child to achieve gradually increased capacity to take responsibility for the maintenance of health and the treatment of illness is a crucial task, specific to pediatric physicians and practitioners. See the Table below for helpful strategies to accomplish this goal.

Table. Strategies to Engage Children in the Outpatient Setting

Speak with the child; not at or to him or her
Speak in a private setting
Determine whom the child would like to be present (younger children will generally prefer parents to be present; children who have been abused by family members may need privacy to facilitate disclosure; most adolescents prefer privacy)
Begin with a nonthreatening topic
Listen actively
Pay attention to body language and tone of voice
Use drawings, games, or other creative communication tools
Elicit fears and concerns by reference to self or a third party
Ask the child what he or she would do with 3 wishes or a magic wand

Data were adapted from Lask B. Talking with children. Br J Hosp Med. 1992;47(9):688-90.

Despite these seemingly simple and cost-effective techniques, recent studies indicate that children are generally passive recipients of medical care, with little opportunity to express their concerns and virtually no attempt to engage them in the creation or implementation of a feasible care plan. In 1 study, children 8 to 15 years of age who had cancer perceived that they "occupy a marginal position in consultations . . . their priorities were of little interest to medicine."

Enabling Effective Child Participation

In the past, children of any age were rarely consulted about their own health concerns. In current Western culture, children are highly valued, yet attention to their autonomous needs, especially when the child is not yet an adolescent, remains challenging. There are many reasons to include children as active partners in their own health care; however, this rarely happens. Some attribute this situation to the dearth of tools to clarify children's conceptualization of health and illness, to assess their capacity for decision-making, to effectively share information with children, and to assess the outcome of shared decision making on the child patient.

Children can be coached to effectively assume the role of a health partner. One study used brief videos, age-appropriate workbooks, and a short (1- to 2-minute) role-play for the child subjects. Simultaneously, the physician and parents were educated on the importance of the child's participation. The goal was to enable children to raise concerns, ask questions, note information, and participate in the creation and troubleshooting of potential problems with the care plan. Coached children preferred an active role in their care and reported better rapport with the physician, recalling significantly greater amounts of information about their medication regimen than controls (77% vs. 47%, respectively). Physicians can encourage the parent to coach the child to be an effective advocate for his or her own health.

The importance of the child possessing effective health communication skills becomes evident when trying to assess and treat a child's subjective symptom, including pain. In the absence of the child's input, it is difficult to understand the nature and severity of the pain; thus, it is nearly impossible to relieve the discomfort effectively and safely. It is well known that the use of patient-controlled analgesia assists with the resolution of pain beyond the dose of medication. The message that the child knows his pain, is in control of his therapy, and is trusted is a powerful therapeutic intervention. Children as young as 4 years of age have used patient-controlled anesthesia effectively.

In many cases, parents mistakenly think that not informing the child is best. Some professionals argue that paternalistic decisions (primarily on the part of the family) to withhold "harmful" information from the child can be justified. This position is not supported in the literature that examines the child's preference for information. One of the most striking was a landmark study of terminally ill children, indicating that children as young as 3 years of age were aware of their diagnosis and prognosis without ever having been told by an adult. The investigator found that adult avoidance of disclosure and denial of difficult information led the child to feel abandoned and unloved. At the same time, the child's response is often to "protect" the "unaware" adults, despite great personal cost; this situation is called mutual pretense and it hurts both parties. By using

whatever information they have, children will continually try to make sense of their situations. An incomplete ability to understand does not justify a lack of discussion with a child who desires involvement in his or her care and decision making.

Children often understand more than has been assumed; increased experience with information they can understand creates a stable framework on which to add new information, promoting the integration of increasingly complex pieces of information. Children need to have usable information, to be given choices (including their desired level of involvement), and to be asked their opinion, even when their decision will not be determinative. Enhanced understanding provides a sense of control, which in turn mitigates fear, reducing the harms associated with illness and injury. Moreover, if the child is asking about the condition, he or she often already knows something is wrong and is checking to see whom to trust. Children who do not ask should be given the opportunity to receive information, but if they refuse it, information should never be forced on them.

Parents are also apparently harmed in the aftermath of nondisclosure to their children. A study of bereaved parents in Sweden indicates that all those who spoke openly with their children had no regrets, whereas 27% of those who did not speak to their children about dying not only regretted their decision but also suffered from an increased incidence of depression and anxiety as a result. Thus, counseling parents about the benefits of disclosure should be invoked when they are reluctant to speak with their child about illness or death.

Adolescents' Roles in Health Care Communication and Decisional Authority

If adolescents are to be given authority for their health care decisions, they must receive thorough, developmentally appropriate, understandable information, to enable an understanding of the condition, what to expect with various tests and treatments, the range of acceptable and practical alternative care plans, and likely outcomes of each option. Only then can adolescents fully participate as partners in their health care.

Because the ability to comprehend and decide is fluid and variable within and between individuals, the assent given by an informed child or adolescent who can weigh the pros and cons of the proposed intervention should be given progressively greater weight compared with parental permission. However, the child's choice and parents' choices may be discordant. Expecting children to adhere to adult priorities and preferences may be illogical; one group of investigators argues that adults' priorities clearly change over the trajectory of adulthood. Thus, if no value set is static, the adolescent's seemingly trivial or superficial judgments may be just as legitimate as any other. They argue that total paternalism toward adolescents' decisions undermines respect for the emerging, autonomous adults they will become and the emotional investment they have in their current values. The values with which adolescents judge their options are applied to an adolescent who holds those values, not to an adult with divergent values. This tolerant model of decision making addresses potentially harmful decisions by giving weight to the adolescent's decision, with the proxy taking the role of educator, discussant, challenger, and shared decision maker.

Overriding the adolescent's decision should be undertaken with great trepidation, using the same criteria as are used to override an adult's choice.

Adolescents and Forgoing "Life-Prolonging" Treatments

Children who have undergone treatments for a condition know the burdens of therapy more intimately than the adults trying to help them. Although they may not appreciate all the hoped-for benefits, their input into treatment decisions is clearly critical for a legitimate weighing of the benefit-burden calculus. When adolescents are able to appreciate the hoped-for benefits, they then also have the capacity to make full-fledged decisions regarding whether to forgo medical interventions. Decisions to forgo life-prolonging treatments made by adolescents have been upheld in courts of law. One investigator found that when physicians oppose these decisions, the courts generally decide for the professionals, prompting a caution to physicians to carefully weigh the likely burdens and benefits before going to court to force treatment.

Adolescent Decision Making: Legal and Ethical Issues

By US law, adolescents younger than 18 years (19 years in Nebraska and 21 years in Michigan) cannot make decisions about their health without their parents' permission with some exceptions, notably emancipated minor status. Emancipated minors are persons younger than 18 years who live independent of their parents, who have taken on the responsibilities of an adult, including financial independence, parenthood, or military service, or who are emancipated by court order. Most states recognize "mature minors" by criteria strikingly similar to emancipated minor status. However, both the age of the patient and the conditions vary somewhat from state to state. Adolescents who are neither emancipated nor mature minors are allowed by some state statutes to give legally binding consent for treatments for limited reasons (examples include testing and treatment for sexually transmitted infections, including human immunodeficiency virus (HIV) infection; drug or alcohol abuse; family planning; blood donation; and mental health care) without parental notification.

Cultural Considerations

Minority and non-English-speaking families often have cultural expectations and nuanced understandings of language that, if not understood and attended to, can substantially interfere with effective medical care and may lead to a decrease in health status for their children. The AAP endorses the responsibility of the practitioner to be aware of and to accommodate the needs of such families. At issue are concerns regarding who gets information, who makes decisions, amount of eye contact, forthrightness, and the need for indirect discussion. It is a good idea to be aware of the general cultural norms and taboos of the dominant subcultures attending the practice. Although there are guidelines for what is "culturally competent," none describes any individual family. Rather than assuming that a family will identify itself a certain way or follow cultural "norms," it is generally safer to ask family members about the etiquette for communicating with them. "How should I give your family medical information about Mary?" "With whom do I share information?" "Who makes decisions?" "Are there topics that should not be directly discussed in your family?" Offering to wait until the relevant persons arrive is culturally respectful.

Members of subcultures that are typically passive with authority figures, who are fearful in medical situations, who make decisions that favor the group over the individual, or who have generally low educational levels may have special needs. These needs may include repeated invitations to ask questions, use of long silences during discussions, accommodation of large groups for information dissemination and health-planning discussions, extra time to consult with others when decisions are to be made, and written summaries or tapes of conversations to facilitate understanding through sharing information with others, particularly if there is limited English language proficiency. See Table 4 in the original guideline document for suggested prompts to elicit culturally related health beliefs, concerns, and practices.

Use of Translators

The availability of trained translators is required by the Joint Commission. Medicaid partially pays for translation services. Well-trained translators are often aware of cultural norms in addition to their language proficiency. Effective use of translators includes the establishment of a framework for collaboration; before the consultation begins, acknowledge the potential for and the desire to prevent cultural missteps. "I may ask you to say some things that you think are not culturally acceptable. If that happens, please let me know and guide me to more appropriately approach these topics." Use of untrained translators, such as bilingual children or other family members who are trying to absorb information and transmit it while emotionally upset, is inappropriate. Nonprofessional hospital employees are also a common source of "translation." Their knowledge of the English language is often limited, their educational levels, even in their own country, may be low, and they too will be assaulted emotionally with confidential and difficult information. There is rarely a debriefing opportunity for these kinds of volunteers in the aftermath of the discussion. Use of untrained translators is, therefore also, an unacceptable option.

Bad News

Bad news can be defined as "pertaining to situations where there is a feeling of no hope, a threat to a person's mental or physical well-being, a risk of upsetting an established lifestyle, or where a message is given that conveys to an individual fewer choices in his or her life." An alternate definition is that bad news is information that "results in a cognitive, behavioral, or emotional deficit that persists for some time." Recognition that much of health care communication is actually bad news will improve attention to its delivery. As an example, although the diagnosis of neurofibromatosis type 1 may not seem to the practitioner to be bad news, the variability of the outcome and the lack of predictability of the disease make this diagnosis very difficult for parents.

Similarly, the need for unanticipated blood tests for a needle-phobic child or the disruption of an unexpected overnight hospital stay, the need to take medications for the rest of one's life for a chronic condition, and many other common occurrences are bad news for families. Greater attention to the empathic delivery of bad news will result in improved skills when the stakes escalate, as in terminal conditions. Communication skills will be well honed and practitioner fear and guilt will not predominate when a bereaved parent states "I remember every aspect of

what was said and how it was said when the doctor told me that my daughter had cancer."

Pediatric oncologists have significant-to-profound discomfort in discussing prognosis, particularly the impending death of their patients. Bereaved parents of trauma victims have reported being told of the death in the hallway, waiting room, or other public area, implying a lack of training of emergency and surgery personnel. When information is delivered poorly, parents perceive a lack of empathy and respect, and memories of this experience may be etched in the minds of the survivors for the remainder of their lives, compounding and prolonging the grieving process. Given the risks of such permanent damage, there is a moral imperative to ensure that preparation for the effective and empathetic disclosure of bad news is routinely integrated into pediatric training.

Good Ways to Give Bad News

Most of the advice about breaking bad news in general applies to the ICU, emergency department (ED), and delivery room settings and to the disclosure of terminal illness. The main difference is the time frame and the intensity of emotion, although even parents of chronically ill children who have survived many previous hospitalizations will also often be shocked (and frequently unbelieving) that the child will not recover this time ("We've been told that before, and he is still here").

Many clinicians believe there is no good way to give bad news. However, research with parents whose children had a wide range of diagnoses provides consistent guidance. See Table 5 in the original guideline document for suggestions for breaking bad news with skill and empathy.

When hearing bad news, parents value a physician who clearly demonstrates a caring attitude and who allows them to talk and to express their emotions. One effective opening to the conversation is to ask, "What do you already know about what is happening to (patient's name)?" Once their ideas are elicited, misperceptions should be corrected. Asking whether they know someone else with this diagnosis or situation and inquiring about their associated experience can be helpful. The latter question assists the physician to be aware of the family's fears and expectations. Pointing out how the child's situation is similar to or different from the previous experience helps parents to better understand the child's likely course.

Parental dissatisfaction with the process of breaking bad news is common. Use of a protocol for breaking bad news can substantially improve the experience. Comprehensive guides for breaking bad news are available. Although needing to inform parents of a chronic, incurable diagnosis may challenge a physician's feelings of competency, parents are most attentive to the affective relationship of their informant, rather than the ability of the informer to "fix it." Parents are able to distinguish the difference between the delivery of the news and the news itself.

One US study in the 1980s found that parents of children with cancer, when hearing the initial diagnosis, desire less information at that time, preferring an emphasis on establishing trust with new caregivers. Parents' trust of advice is built by acknowledging the grief, anxiety, and fear the family is experiencing and

inviting them to share their feelings and ask questions. Gradually sharing additional illness and treatment information, supplemented by written or taped materials, and providing a means to contact the physician when additional questions arise, is also greatly appreciated. Many parents now are asking for e-mail contact and, in some instances, this is a reimbursable service.

When parents (predictably) become upset during the informing interview, acknowledge their grief and fear by waiting until their attention turns back to the discussant, then state (for instance):

"I can see you were not expecting this." (Silence)

"You seem quite upset; I would be, too. (Silence.) Do you know anyone who has had this illness? (Silence.) How did things go for them?"

Facial tissues are essential equipment. Parents want hopeful and positive things said about their child, and an opportunity to touch or hold the child, particularly newborn infants or children from whom they have been separated during a transport. They need recognition by the physician of the child's unique value as an individual first and as an ill or injured person second. Speaking of the child as if he or she "is" the diagnosis is hurtful.

As time progresses, parents also appreciate emotional support and affirmation of their efforts and ability to care for the child. "Your child is lucky to have you for parents! I can't imagine anyone doing a better job than you two!" Harsh or judgmental statements about the child, the parents, or their behaviors are unhelpful.

Communication in the ICU and ED

Bad News in the ED

In the ED, parents often arrive separately from the child. If they are available by telephone, let them know the child is seriously ill/injured, but do not disclose death over the telephone unless the parent is insistent. Suggest they come in as soon as possible and bring their spouse and a close friend with them. Ask them to be careful and to consider letting someone else drive, because they are at an increased risk of having an accident because of their appropriately upset emotional state.

If a child is undergoing resuscitation when the parents arrive at the ED, it may be appropriate to offer the parents the opportunity to be with the child. The majority of families offered this option accept and feel much better knowing that "everything was done" and that they were there in the child's last moments of life. Parents should know they do not have to go into the resuscitation area if they choose not to; affirmation should be provided indicating that loving and good parents decide either way. If the parents choose to be present, a staff member should be assigned as a dedicated escort. This individual should tell them what they will see and let them know they can leave at any time. Parents should be informed that they will be asked to leave if they interfere with the team's function or seem to be harmed by being there. When in the room, the escort explains the

role of each person present, what is being done, then affirms that, despite all that is going on, this is still their child (use the child's name) and that he or she may be able to hear the parent. The escort can suggest the parents touch and speak to the child, assuring him or her of the family's love.

An even more challenging task is to inform families of trauma victims that their previously healthy child is dead. One group of investigators studied the experiences of bereaved families of child and adult trauma victims. The findings and recommendations were consistent with those for ICU patients. The most important attributes of the communication, from the parents' perspectives, are the attitude of the informer, clarity of the message, privacy of the conversation, and the ability of the informer to accurately answer parents' questions. Many parents recounted positive experiences, primarily of having caring hospital and prehospital staff. Physicians garnered most of the negative comments. Rank and attire were of minimal concern to these families.

After greeting the parents and escorting them to a private area, have someone who has directly participated in the care of their child speak with them. Sit down and bring tissues. Begin by asking what they know so far. Ask when they saw the child last and what he or she was doing at that time. Explain any factual details that are known about what happened at the scene and what has been done so far in the resuscitation. There are 2 choices at this point; the first is immediate notification of the death, offering to escort the parents into the room to be with the body, and explaining what was done and that the child's injuries were too severe to survive but reassuring them that everything that could have been done to save the child's life was done. Alternatively, there can be a staged disclosure, initially telling them that the child is very severely injured and at risk of dying, but that everything possible to save him is still being done. Tell them you are going to check on the rescue team's progress, leaving a team member in the room with them; make sure the rescue area is cleaned up and that the child's body is presentable. Leave some of the tubes in place to demonstrate the efforts that were made to save the child's life. Call the chaplain and the social worker if they are not on the scene. Then, go back and inform the parents of the child's death a few minutes later. In the case of sudden, unexpected, and overwhelming illness or death, parents will likely be shocked, highly emotional, angry, and suspicious. This reaction, although difficult to endure as the perceived target of their animosity, is certainly understandable. A parent might blurt:

"But I put Juanita on the school bus this morning. She can't be dead!"

Offer to take parents in to see their child, and ensure a member of the resuscitation team is available to provide the specifics of what was done and to answer any questions. If feasible, move the body and the family to a private area to maximize privacy and minimize disruption; allow families to have some private time with the body. Ensure an appropriate environment, including a rocking chair, support persons from the family, and a limited number of members of the care team, if desired by the family. Do not rush them. Experience indicates that 2 to 3 hours is the maximum time most families want to remain with the body; 15 to 20 minutes is more common.

Communication in the neonatal intensive care unit (NICU) and pediatric intensive care unit (PICU)

Communication within an NICU or PICU generally involves bad news in a very foreign environment, virtually always with large numbers of unfamiliar health care professionals. Guidelines have been promulgated to suggest important ways to support families of ICU patients. See Table 6 in the original guideline document for suggestions regarding family-centered communication and support in the ICU.

Understanding how parents cope with bad news may prevent some judgmental conclusions and may assist ICU caregivers to be effective communicators with families. See Table 7 in the original guideline document for a list of coping mechanisms, both adaptive and maladaptive, of parents with critically ill children.

The stakes involved in having a child in the ICU and the constant uncertainty make negative reactions understandable. Parental sources of stress include seeing their child in pain, frightened, or sad, and the inability to communicate with the child. Increased attention to the fulfillment of parental needs can improve relations between parents and ICU staff.

Special Communication Considerations in Terminal Illness

No communication is more difficult than telling a parent that his or her child will die. However, in many instances, painful as it is, parents may be hoping doctors will do just that. Parental recognition that one's child is suffering, disproportionate to the likelihood of benefit, is extremely distressing. However, it is a rare parent who will challenge the physician who continues to hold out hope for "cure" or prolonged life. Parents and adult patients expect physicians to recognize and discuss the need to change the goals of care. In 1 study, 45% of parents of critically ill children thought it may be time to stop attempts to treat the illness before the physician brought it up, but none broached the topic. Many physicians, however, wait until they perceive the family or patient is "ready," leading to additional emotional and physical suffering, including a prolonged dying process. Mixed messages from multiple consultants, particularly in the ICU setting, can be extremely confusing and upsetting for families, often leading to poor decision making as the parents (understandably) hold on to the most hopeful messages. Having a clear captain of the care team, one who is evaluating the situation as a whole, particularly as death nears, is extremely helpful in preventing such problems.

Bad News in the Delivery Room

Despite increasing accuracy and availability of prenatal diagnosis, a pediatrician can be confronted in the delivery room by a child who is too immature to survive or who has anomalies that are incompatible with life; attempts at resuscitation would be inappropriate in these situations. When prematurity is the problem, the parent is generally already aware of this. Introducing oneself and providing "a warning shot" may be helpful.

"I am Dr. _____ and I am the pediatrician who was called by your physician to care for your infant. My team and I have experience doing everything possible to help premature newborns. Based on your history and our examination, it seems, unfortunately, that your daughter was born too early to survive for very long, no matter what we do. (Pause) I am sorry. I really wish it were different. At

this point, we are ensuring her warmth and comfort. (Pause) Does she have a name? Would you like to spend some time with her and hold her?"

Point out the infant's normal features. Important things not to say at this time include asking when the mother noted her premature labor or asking about factors that may have triggered premature delivery. Blaming is unhelpful and unnecessary; avoidance of a recurrence can be accomplished at a future time when the information can be seen as helpful and can be absorbed.

For the near-term child with lethal anomalies, the diagnosis has typically been made before delivery. In this case, it can be helpful for pediatricians to ask parents what they know and provide confirmation of what they see. Goals of care should have already been established; in some settings, a prenatal hospice program may have been set up and available for support during the delivery. If not, or if the diagnosis is unexpected, a "warning shot" is needed, followed by empathic and clear disclosure. Hovering and whispering about the infant only adds to the panic and confusion.

"I am Dr. ____ and I was asked to help care for your son. He has beautiful hands! And he also appears to have some unusual characteristics. Did you or your obstetrician have any concerns or suspicions that something may have been different about your baby before his birth?"

If the prognosis or diagnosis is not clear, the infant will likely be brought to the NICU for additional evaluation and management. An explanation of what will be done, how long it will take, when the parents can visit, and when more will be known is important. If the child has a clearly lethal anomaly (e.g., anencephaly), the child should not be separated from the parents unless that is their preference, and the process of palliative care should begin immediately. Pointing out the normal features of the child and ensuring the parents do not blame themselves for the anomalies are important therapeutic interventions. Asking whether parents wish to bathe or dress their child or have siblings hold their child helps families accept the newborn. If the infant is alive, attend to its comfort with warm blankets and maternal skin contact, if desired. Suggest making a hand mold or print, cutting a lock of hair, or taking photographs. Offer to call a chaplain or the parents' own clergy, if they prefer, to assist them to explore meaning and to help with any rituals. Give them time to be with the infant or the body in a private place for as long as they desire. Offer help to call friends or family if they choose. Ensure bereavement follow-up.

In the NICU and PICU, parents are often asked to participate in the decision-making process regarding the use of "life-prolonging" measures. Little research addresses effective and compassionate ways to communicate about stopping critical care interventions and changing goals of care, although much research documents dissatisfaction with current methods. The usual way of addressing the failure of medical therapy can be very problematic and may generate thoughts or conclusions that are unintended but potentially devastating. Table 8 (in the original guideline document) presents common medical statements, how they may be perceived, and suggests alternatives.

Informed Consent, Communicating Risks, and Benefits of Research

Sometimes, when conventional treatment has failed, clinical trials are available. Although parents often state their motives to enroll their child in research are altruism and/or the desire to learn more about their child's disease, it is interesting to note that, when they are in an outpatient setting and less rushed to make a decision, participation rates in clinical trials are lower than in inpatient settings. It is clearly difficult to achieve truly informed consent for medical care or procedures, let alone clinical research, when death is likely; strong emotions govern such situations. The need to explain complex constructs of risks and benefits, randomization, physiology, and often, pharmacology to lay people is daunting. Nevertheless, there is still an obligation to make a valiant effort to obtain truly informed consent. Too often there is a problem of therapeutic misperception, representing that the purpose of the research is to treat the patient rather than benefit future patients. Indeed, therapeutic misperception may sometimes even be fostered by investigators. However, a recent analysis of cancer trials found that there were "insufficient data to conclude" that enrollment in clinical trials resulted in improved outcomes. According to the Institute of Medicine Committee on Clinical Research Involving Children, consent, permission, and assent should be viewed as a process of communication, encouraging questions at the initiation and throughout treatment to assess understanding and ensure lack of coercion in ongoing participation. These recommendations are based in part on 2 other important, recent reports on research ethics.

A study of consent for childhood leukemia trials found that not providing information, and lack of understanding of information presented, hampered the achievement of informed consent. For instance, randomization was not mentioned in 17% of cases, and parents did not understand it 50% of the time, despite efforts to explain the concept. Similarly, 18% of parents lacked understanding of the right to refuse to participate (attempted explanation, 97%) and 20% did not understand the right to withdraw from the study at any time (attempted explanation, 72%). In another study, parents did not understand the existence or details of treatment alternatives. Health literacy is a problem for much of the adult US population, not just parents.

Children being offered the opportunity to participate in clinical research trials must be asked their opinion and must give permission to proceed. In fact, the requirement for affirmative child assent is codified in the Current Federal Regulations. The opportunity to provide assent implies the ability to dissent as well; dissent must be taken seriously but is not considered to be determinative, when rendered by the child, if the trial holds realistic promise for a beneficial outcome. These concerns and needs must be anticipated as routine and accommodated. Clinical investigators need explicit training regarding how to obtain truly informed consent. Suggestions to help improve communication about clinical trials are in Table 9 in the original guideline document.

In the setting of research with a potentially terminally ill child, emotions run high. Parental and clinician ability to judge the situation on the objective merits of the alternatives, within the framework of long-held values, is severely challenged and rarely accomplished. An altruistic child may prefer to continue on to benefit others, regardless of his or her own outcome. These children are ideal candidates for research. However, others want desperately to control their destinies and to enjoy the time remaining. Parents' need to sustain life, often at all costs, can blind them to the child's need to enjoy it. It is the clinician's obligation to ensure that

the risks and benefits are communicated in an unbiased way, while giving recommendations based on disclosed priorities and experience. Decisions should incorporate the views of the child, parents, and other caregivers who know the child well. Additional research is desperately needed to ensure a process that enables truly informed consent.

Presenting Palliative Care as a Viable Alternative to Research Participation

At such vulnerable times, parents are often told that the "only" alternative to enrollment in experimental therapies is "doing nothing," an alternative that is never attractive and is also never true. Each treatment option should be evaluated based on the likely (not just hoped for) outcomes in this individual child's case, given his or her illness history and comorbidities, and the known and possible burdens and complications, including pain, isolation, fatigue, and missed opportunities. The merits and burdens of pursuing palliative goals of care without further attempts to reverse the disease versus experimental or "innovative" (uncontrolled research) treatment must be clearly explained to ensure that a choice is truly being offered.

Palliative care can be provided concurrently with life-extending measures or can be the sole focus of care. Palliative care is intensive care, addressing the whole child within the context of self, family, and community. Palliative care attends to spiritual, physical, emotional, and social needs of the patient while also addressing the needs of parents, siblings, and others affected by the child's illness and ultimate death. Palliative care can facilitate an excellent quality of living in the face of a short life expectancy, ensuring that the child and his or her family live fully, despite being in the shadow of inevitable death. Children can even live longer than expected when effective palliative care is offered because of renewed hope and relief of symptoms that are too often ignored in other treatment paradigms.

Postmortem Communication

Parents are generally supported by family, friends, the community-based medical home pediatrician, and their congregational clergy after the death. However, they often feel cut off from the people with whom they developed an intense bond in the hospital; the last people to assist them to care for their child, the people who guided their initial acknowledgment of their child's death. Even small tokens of continued concern have a huge effect on families. In a study of bereaved survivors of adult patients, a condolence card, signed by direct care providers and mailed 2 weeks after the death, had a profound impact. Ninety-four percent of the recipients still had the card in an easily accessible place 1 year later. One woman whose husband died in the ED stated that the card helped her cope with his unanticipated death, because "at least I know he died among caring people." There is published guidance for physicians about how to write a condolence card, but even a signature will suffice.

Sometimes, especially when practitioners have become extremely close to the patient, attending the memorial or funeral service may be appropriate. This act serves to let the family know that the concern and attachment they perceived were real; it may also allow some healing for the practitioner, who otherwise may

"burn out" from the emotional exhaustion of the investment in children who die and their families. Giving oneself permission to love and let go is important, and societal rituals may assist in the resolution of the professionals' grief as well. Families are generally overcome with appreciation when the physician attends the memorial or funeral and can be resentful when they do not. The AAP endorses an active role for the pediatrician in providing bereavement care.

Autopsies as Communication Opportunities

Particularly if an autopsy is performed, it is advisable to have a postmortem conference with the parents (and sometimes siblings as well) approximately 6 to 8 weeks after the death. As parents reflect on the whirlwind events of their final days with their child, numerous questions arise. They need a vehicle to have these questions answered efficiently. If an autopsy is performed and there is no opportunity to hear and discuss the results, parents may become suspicious that the medical establishment was "experimenting" on their child. Moreover, parents may have requested the autopsy to assist in family planning or to determine the need to do screening procedures on close relatives; thus, they may be awaiting the results anxiously. An in-person meeting allows the treating physician to answer all the family's questions, translate the autopsy findings into understandable lay language, and importantly, to check on the well-being of the parents and siblings. The family and the staff appreciate coordination of the timing of this meeting so all important members of the care team can attend. Long-term follow-up may include an annual card on the child's birthday or anniversary of the death, invitation to annual memorial services at the hospital, or other locally appropriate options.

Medical Error Disclosure

Medical errors are increasingly in the public eye. Communication about medical errors is one of the most challenging aspects of health care, yet parents exhort caregivers to be forthright and timely in revealing the mishap. Training on how to approach patients and families about the occurrence of a medical error can increase family and patient satisfaction regarding these situations and can substantially decrease the medical malpractice payouts related to such occurrences. (Multiple case studies are available at <http://www.sorryworks.net>.)

Physician Self-Care

Medicine is a challenging and rewarding profession. It requires lifelong learning, not only from books, journals, and courses, but also from attention to interactions with patients and families. Physicians have a difficult job; the responsibility to communicate effectively and efficiently to clarify the diagnosis, consider psychosocial and existential concerns, respect family and other supporters' needs, and to come to an agreed-on plan of care is substantial and can be overwhelming. Allowing time between patients and debriefing conversations with staff, increased physician education on communication, and improved payment for counseling time can help.

Summary

Effective, empathic communication is an essential skill for physicians caring for pediatric patients and their families. It can lead to improved outcomes for children, their families, and physicians themselves. Communication deserves a place at center stage for pediatric education, practice, and research.

CLINICAL ALGORITHM(S)

None provided

EVIDENCE SUPPORTING THE RECOMMENDATIONS

TYPE OF EVIDENCE SUPPORTING THE RECOMMENDATIONS

The type of evidence supporting the recommendations is not specifically stated for each recommendation.

BENEFITS/HARMS OF IMPLEMENTING THE GUIDELINE RECOMMENDATIONS

POTENTIAL BENEFITS

- Effective health care communication is an essential tool for accurate diagnosis and for the development of a successful treatment plan, correlating with improved patient knowledge, functional status, adherence to the agreed-on treatment regimen, improved psychological and behavioral outcomes, and even reduced surgical morbidity.
- Improved communication with patients and family enables more effective, efficient, and empathic pediatric health care.

POTENTIAL HARMS

Not stated

QUALIFYING STATEMENTS

QUALIFYING STATEMENTS

The guidance in this report does not indicate an exclusive course of treatment or serve as a standard of medical care. Variations, taking into account individual circumstances, may be appropriate.

IMPLEMENTATION OF THE GUIDELINE

DESCRIPTION OF IMPLEMENTATION STRATEGY

An implementation strategy was not provided.

INSTITUTE OF MEDICINE (IOM) NATIONAL HEALTHCARE QUALITY REPORT CATEGORIES

IOM CARE NEED

End of Life Care
Living with Illness
Staying Healthy

IOM DOMAIN

Effectiveness
Patient-centeredness

IDENTIFYING INFORMATION AND AVAILABILITY

BIBLIOGRAPHIC SOURCE(S)

Levetown M, American Academy of Pediatrics Committee on Bioethics. Communicating with children and families: from everyday interactions to skill in conveying distressing information. *Pediatrics* 2008 May;121(5):e1441-60. [256 references] [PubMed](#)

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GUIDELINE AVAILABILITY

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Print copies: Available from American Academy of Pediatrics, 141 Northwest Point Blvd., P.O. Box 927, Elk Grove Village, IL 60009-0927.

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None available

PATIENT RESOURCES

None available

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